How do families participate in the study?

There are two main parts of the study. Children with DBMD and their families are being identified through the records of clinics and hospitals statewide. Information will be copied from these records and used in the study. Parents do not have to do anything to participate in this part of the study. The second part of the study is a family interview that takes about 30 minutes. The interview focuses on things like support services and family experiences that are not likely to be included in medical records. Families will be told about the study in detail, and asked to give their consent to participate in this part of the study.

For both parts of the study, strong steps are taken to protect the privacy of medical records and interviews.

Why should our family do the interview?

Because it is important that the study reflect the experience of all Georgia families affected by DBMD, including yours. The more complete the study, the more useful it will be for research and public policy. Your family's experience, together with that of all the other families affected by DBMD, can help improve the care that children with DBMD receive in the future.

The family interview is completely voluntary. Your decision to participate or not will not affect the medical care or services your child receives.

In Georgia

For more information about MD STAR*net* in Georgia, contact:

Marques Harvey, MPH
MD STAR*net* State Coordinator
Phone: 404-498-2761

CDC is working with:

- Children's Healthcare of Atlanta (Atlanta)
- Medical College of Georgia (Augusta)
- Roosevelt Institute for Rehabilitation (Warm Springs)

For more information about DBMD and MD STAR*net*:

www.cdc.gov/ncbddd

WHAT IS

MD STAR*net*?

SAFER · HEALTHIER · PEOPLE™

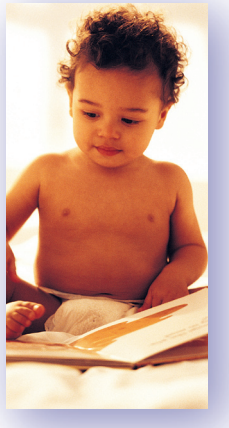
FOR FAMILIES

MD STAR*net*

…is the Muscular Dystrophy Surveillance Tracking and Research Network, a study of patients with muscular dystrophy and their families. Right now, the study is being done in five states: Georgia, western New York, Iowa, Colorado, and Arizona. As the study goes on, other states will be added.

Muscular Dystrophy

If you are a parent or family member of someone who has muscular dystrophy, you probably already know that muscular dystrophy is actually a whole group of disorders caused by a change in a particular gene. Over time, the muscles of people with muscular dystrophy get weaker and weaker.



Duchenne/Becker muscular dystrophy (DBMD for short) is the most common kind. Out of every 3500 to 5000 boys born, one will have DBMD. This means that of the 2 million boys born in the United States each year, about 400 to 600 have DBMD. Although it is possible for girls to have DBMD, it is very rare.

What is the purpose of MD STAR*net*?

Although scientists have done a lot of research on DBMD, many questions remain. The goal of MD STAR*net* is to help answer some of these questions. For example:

- At what age do the signs and symptoms of DBMD first show up?
- How many people with DBMD are living in Georgia and the other states where MD STAR*net* is being carried out?
- Is DBMD equally common in different racial and ethnic groups?
- What factors affect the severity and course of DBMD? Does the type of abnormal gene matter? What about the type of medical care patients with DBMD receive?
- What medical, educational, and social services are patients with DBMD and their families receiving?
- Does the health care that people with DBMD receive vary from area to area? Do different population groups receive different health care?

How will MD STAR*net* help children with DBMD and their families?

MD STAR*net* aims to improve the health and quality of life of all DBMD families by describing the health and service needs of patients and their families. This information will help communities provide better resources, services, and support. It will help families and their allies advocate for resources and services.

Who is doing the study?

A federal agency, the National Center on Birth Defects and Developmental Disabilities, which is part of the Centers for Disease Control and Prevention (CDC), in Atlanta. CDC is working with researchers in 5 states: Arizona, Colorado, Georgia, Iowa, and western New York.